NATIONAL ME / FM ACTION NETWORK

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Quest

Quest #58 March/April 2003

Fibromyalgia Syndrome Consensus Document – Update

Marjorie van de Sande, Director of Education

We are pleased to announce that all members of the expert consensus panel have approved the final revisions for the FMS consensus document and the document has been submitted to a medical journal.

The diagnostic protocol includes a clinical definition for FMS, a discussion of the major features, and the clinical evaluation of the FMS patient. The treatment protocol section includes goals and principles/guidelines, lifeworld adjustments, guidelines for self-powered FMS exercise programs, pharmacological treatments, and alternative/ complementary approaches. There is a comprehensive discussion of the research on FMS. In addition, there are a number of appendices including worksheets, scales, questionnaires, appropriate stretches and exercises for FMS patients, how to assess occupational disability, etc.

We are very pleased with the final document entitled, "Fibromyalgia Syndrome: Clinical Case Definition, Diagnostic and Treatment Protocols: A Consensus Document". We would like to give our sincere thanks to the Expert Consensus Panel for donating their time and expertise to the development of this document. The Expert Consensus Panel had full autonomy over the document and include: Dr. Anil Jain and Dr. Bruce Carruthers: co-editors, Dr. Jon Russell (USA), Dr. Thomas Romano (USA), Dr. Dan Heffez (USA), Dr. Daniel Malone (USA), Dr. Donald Seibel, Dr. Stephen Barron, Dr. Stuart Donaldson, Dr. James Dunne, Dr. Emerson Gingrich, Dr. Frances Leung, and Dr. David Saul. It was a privilege to work with the FMS expert panel as Consensus Coordinator.

You Can Help

We are sending out information to the medical and legal communities about the **ME/CFS: Clinical Working Case Definition, Diagnostic and Treatment Protocols.**

Please continue helping us to disseminate the information about the new ME/CFS definition (published February 1, 2003) by sending us the names and addresses of doctors and lawyers you are aware of so that we can let them know of this exciting news. There is still much work to be done but with your help and support, we will succeed.

Lydia E. Neilson, President CEO

OOOOOPS!

In QUEST 57 (Jan/Feb 03) **Information for ME/CFS Physicians - Cognitive Function in ME/CFS**, Page 3, the wrong contact information was inserted. The correct Contact details are as follows:

Ellie Stein MD FRCP(C), Psychiatrist,

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Trouble Remembering? Testing is Now Available in Canada to Assess Cognitive Problems in ME/CFS

Ellie Stein, MD FRCP(C)

The E Team ***- A Joint Venture of Independent Professionals United in the Quest to Bring Validation, Hope and Healing***

Gerard Alberts M.Ed C.Psych; Diana Monea Optometrist; Eleanor Stein MD, FRCP(C); Matthew van Olm MD FRCP(C); and Anne Woolliams Aud (C) (All located in Calgary, Alberta)

Specialized Multidisciplinary Assessment for Cognitive Symptoms and Related Problems Associated with: Myalgic Encephalomyelitis / Chronic Fatigue Syndrome, Fibromyalgia, Multiple Chemical Sensitivity, and Toxic Chemical and Mold Exposure

One of the most frustrating experiences for people with the above disorders (ME/CFS, FM, and MCS) is the absence of objective findings that support their subjective illness experience. Some of the symptoms such as pain and fatigue are internal experiences. Other symptoms such as irritable bowel and sleep disorder are overlooked as benign by many practitioners because they are not progressive or lethal. Cognitive dysfunction including poor short term memory, difficulties with word finding, problems with multitasking and effortful thinking tasks is one of the most disabling and least validated problems in ME/CFS and FM. The research on cognitive function in ME/CFS, FM and MCS has consistently shown that there are objective cognitive deficits however these results have been slow to influence clinical practice. Despite the consistent research findings of dysfunction, many practitioners continue to view the cognitive complaints of ME/CFS, FM, and MCS patients as evidence of increased "somatic concern"; in other words, a psychological problem.

Many people with complaints fall into the "normative" range. The normative range is enormous. It encompasses 87% - 95% of the population (1.5 - 2 standard deviations from the mean) depending upon the cutoffs used. Therefore a person scoring in the 90th percentile before becoming ill or being exposed to a toxin who experiences decreased function to the 50th percentile during illness will be classified as "normal" despite the fact that his/her performance has decreased significantly and despite the fact that he/she may no longer be able to do the job or activities which were previously rewarding.

Protocol Development

Our test protocol has been designed drawing heavily on the research of **Dr. Kaye Kilburn**, a professor at the **University of Southern California** and the clinical work of psychologist **Dr. Nancy Didriksen** who runs a busy private practice in Dallas, Texas. Our testing goal is not only to ascertain whether areas of functioning are below the normative range but to compare areas of functioning eg. memory which is usually affected in ME/CFS and related disorders with areas of functioning that are rarely affected eg. abstraction, vocabulary. This allows a comparison of a person to him/herself in addition to other people. Interestingly the cognitive profiles in ME/CFS, FM, MCS and certain toxic exposures are similar. For this reason we decided to combine many of the tests reported in the literature as being sensitive for each of the disorders into one large protocol and use the same protocol for every client.

Protocol Components

The psychological component, including cognitive testing, will be administered by **Gerard Alberts**, a chartered psychologist with extensive experience in psychometrics and other aspects of psychological evaluation. Cognitive effects are perhaps some of the most misunderstood and questionable symptoms of those suffering from ME/CFS, FM, and MCS. Psychometric testing can provide valid and reliable data to support patient reports of cognitive problems. Well-established, standardized tests and procedures are used to provide objective results in efforts to validate cognitive symptoms such as poor short-term memory, attention and concentration problems, slowness in mental processing, problems with word finding, and other aspects of verbal and nonverbal performance and memory. This testing is the most time-intensive component of the multidisciplinary assessment. It is extensive and takes several hours to complete, which can be very tiring for the patient. However, testing sessions can be arranged to suit one's schedule and energy level. The team approach allows results to be interpreted and understood in the context of symptoms assessed from various professional perspectives. A report of findings is provided with recommendations for improving workplace performance and/or quality of life. These may include both traditional and alternative interventions.

Dr. Diana Monea (optometrist) will conduct the visual component of the protocol. The effects of toxic exposure, ME/CFS and FM on vision are frustrating and chronic. Since 80% of what we learn is through vision, visual impairments affect every waking moment and can be debilitating as one tries to work, study or parent. The visual symptoms may include: dry eyes, sensitivity to lights, fluctuating and fading of vision, eye pain, loss of vision or color vision changes. The visual consultation involves digital documentation of the corneal map for dryness, retinal photos for signs of eye disease, refractive testing, visual field to determine any visual loss, and color vision assessment. All assessment results are stored digitally and can be e-mailed if necessary to treating professionals. This consultation is a complete eye-health assessment, followed by a visual consultation.

The psychiatric component of the assessment will be done by **Dr. Eleanor Stein**, a child and adolescent psychiatrist by training with a special interest in ME/CFS, FM, MCS and toxic exposure in her practice. She will undertake a focused history of the presenting symptoms including a detailed history of the areas that are affected by these diseases and a careful review of symptoms to rule out other causes of the problems. She will also conduct a psychiatric interview to establish whether psychological and/or psychiatric issues are a part of, secondary to or independent of the physical health problems. She will make psychiatric diagnoses if appropriate . This assessment will also include recommendations for further testing if appropriate and education regarding the benefits of careful self observation as a way of figuring out what makes symptoms better and worse. Dr. Stein is currently using conventional psychiatric treatments as well as a functional medicine approach to rehabilitation.

Anne Woolliams (audiologist) will conduct the audiological component of the assessment protocol. The effects of toxic exposure ME/CFS and FM on the auditory-vestibular system can be subtle to severe. ME/CFS and FM can cause significant balance and equilibrium problems, hearing loss, auditory processing dysfunction, and tinnitus (ringing in the ears). The auditory-vestibular system is one of the most sensitive systems within the body to toxins and may begin to show signs of significant destruction before any other signs of toxicity may be seen. The audiological assessment within the entire toxic exposure ME/CFS and FM evaluation includes several direct measures of the integrity of the auditory-vestibular system. Hearing thresholds—the softest sounds, which can be heard—are measured, as well as the state of the actual cells within the inner ear and how effectively sound is transmitted from the inner ear to the level of the brainstem. These sensitive evaluative procedures allow us to measure the function of the auditory-vestibular system and correlate the results with the severity of damage to the ear from toxic exposure, ME/CFS and FM.

The pulmonary and environmental exposure assessment will be conducted by **Dr. Matt van Olm,** a respiratory physician. As the first port of entry into other parts of the human body, the lungs are often the first organ system to be affected by environmental toxins. A detailed assessment of an individuals' home and work environment and environmental medical history and experiences throughout their life can help determine how health has changed, and how corrections can be made. This part of the assessment will include a detailed environmental questionnaire, a focused physical exam, review of the findings of pulmonary function testing (ordered as part of the protocol) and blood oxygen saturation measurement at rest and with exercise. Dr. van Olm has considerable experience diagnosing and treating patients with sulfur dioxide and toxic mold exposures. The addition of allergy assessment and lymphocyte activation testing can further refine this essential process.

Referrals

Self-referrals from Canadian residents are accepted but before testing we will need some communication with your family doctor (we are currently designing a short questionnaire for them to complete). The most important consideration is diagnosis. Our equipment and test selection is designed specifically to assess cognitive dysfunction and related symptoms in people with ME/CFS, FM, MCS and certain toxic exposures.

Being based in Calgary, we are especially interested in clients with health and cognitive problems following toxic mold exposure. We will not accept referrals for neuropsychology (trying to find out which part of the brain is affected) or for other unrelated disorders affecting cognition such as head injuries or neurological disorders. Note that although in most cases we will be able to confirm whether you have objective findings consistent with ME/CFS, FM, MCS or toxic exposure, cognitive testing cannot prove the cause of your condition nor can it predict whether your symptoms will improve with time and optimal treatment.

The Procedure

All potential referrals should be directed to the office of Gerard Alberts, the E-Team psychologist. He will explain the time requirement, the procedure and the cost. You must allow 12 - 15 hours for in person assessment time and additional time for transportation and to complete questionnaires. With adequate notice, we can book your appointments to suit schedule (eg. out of town clients) and energy needs.

Payment

The medical components of the assessment: psychiatric interview, pulmonary exam and pulmonary function testing is covered by Canadian provincial health care plans. The psychological, visual and audiological assessments are not covered. Most insurance plans will pay a portion of these costs. Upon request we can provide you with a list of the test procedures to submit to your insurer. In most cases there will be an outstanding portion of the fee that will be billed directly to you, the client. Half of the total fee is payable at the time you sign the informed consent to undertake the ETeam protocol and half is payable when you receive the final report.

Location

The ETeam is located in Calgary, Alberta though two of our members have offices in other cities (Anne Woolliams in Edmonton and Diana Monea in Regina). We welcome and can accommodate out of town clients with sufficient notice. We are very excited to be offering this much-needed and new service. For more information call: **Gerard Alberts** at **Alberts and Associates** and ask about cognitive testing for effects of chemical or mold exposure, Multiple Chemical Sensitivity, Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia
(403) 254-840 or **albertsg@shaw.ca**

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Investigations & Surveillance in LTD Claims

David Lackman, Lackman, Firestone Law Offices (Toronto),
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A number of years ago, I represented a disability claimant – I'll refer to her as Ms. Smith – who, somewhat ironically, had been employed for many years as an administrator for a major disability insurance company. She was a bright and rather serious, no-nonsense type individual who, in addition to being a full-time worker, was the matriarch of a family which included a working husband and grown children living at home.

Ms. Smith came to me when her disability benefits were terminated by her employer-insurer. She had originally applied for and received LTD benefits because of a disabling back condition which seriously compromised her in the performance of her work. She maintained all along that, due to debilitating and restrictive pain, and its effect both on her ability to function physically and to concentrate, she could not carry out even the more sedentary duties of her own occupation or any other occupation. The insurer, on the other hand, viewed things differently when it terminated her benefits despite medical evidence that was reasonably supportive of disability. I was therefore retained by Ms. Smith to sue the insurer.

It has long been my practice when meeting with new LTD clients, to make them aware of the many ways that insurance companies test the validity of claims, not only during the claims process itself but also during the litigation that follows a denial of benefits. For example, I point out that insurers pursue medical examinations from time-to-time since they are not bound to accept the opinions of claimants' own physicians, or they may be looking to more comprehensively evaluate the person's "functional capacities" through specialized assessments. More to the theme of this article, however, I also point out that insurers undertake surveillance and investigations of claimants, particularly when litigation has begun, and that if the activities observed by investigators or reported to them by neighbours are inconsistent with the claim of disability – whether because of the type of activity involved or level of exertion observed, or both – the insurer is going to try to find this out.

I had this very discussion with Ms. Smith during our initial meeting.

The litigation in Ms. Smith's claim went on for several years. In those days, we didn't have court-imposed case management or mandatory mediation so things tended to drag on. At a point just weeks away from trial, I received a surprise invitation from the insurer's counsel to meet with her at her office, "and bring popcorn". It did not take years at the plaintiff's bar for me to know that this could mean only one thing – and it wasn't a seat at a private screening of the next John Grisham film. Under the procedural rules at the time, the defence was not obligated to disclose surveillance films to plaintiff's counsel prior to trial; the films could be introduced for the first time at trial for the purpose of impeaching the credibility of the plaintiff. However, defence counsel's approach in this case was, admirably, to see whether a potentially-costly trial could be avoided altogether rather than to shock-and-awe the plaintiff in court.

A video that I learned had been taken only a few weeks earlier following a heavy snowfall, was played for me at defence counsel's office. It showed Ms. Smith engaged in yeoman efforts, over the course of almost 30 continuously-recorded minutes, throwing shovels-full of snow off her home driveway. I was exhausted just watching her. The yeoman efforts that immediately followed on my part, of course, were directed toward: (1) maintaining my composure; (2) banishing the thought in the minds-eye of cynical defence counsel that my client was having anything other than one of her very occasional "better" days; and (3) instilling the notion that my client had more than likely paid a painful price for her actions in the ensuing "bed-ridden" days.

The claim settled without trial. It was clearly in the client's interests to avoid a trial in the circumstances. Ms. Smith's initial, somewhat defensive reaction to the videotape was to query why I, as her counsel, did not warn her that the surveillance was being conducted. I had to politely remind her about our discussion during the initial meeting, and further point out what I would have thought to be obvious – that insurers and their lawyers do not typically alert claimants and their lawyers that investigations and surveillance are being carried out. She went on to explain that she actually recalled the day well. She had repeatedly asked her husband and children to clear the snow off the driveway, and none obliged. So, she took the task upon herself with two objectives in mind: to get the driveway cleared; and to make a point to her family that she was not going to wait forever and would instead do it herself despite her disabling condition. She also recounted how, in fact, she did pay the price in pain over the next days.

I could, of course, have led evidence at trial in an attempt to "explain" the videotape. And I could have made argument to the court that Ms. Smith clearly felt she had nothing to hide, and that 30 minutes of videotape did not constitute a fair or representative picture of her true limitations, restrictions and pain over the past years. However, the difficulties created by such surveillance would have made a trial unduly risky for several reasons, including: Ms. Smith had asserted all along, to her doctors and in her own pre-trial testimony, that she was physically incapable of anything approaching the types of movements and endurance seen in the video, and that she could not carry out even sedentary tasks; her own doctors, on cross-examination, would have had difficulty reconciling the histories they obtained, their clinical examinations, and the opinions they had given in their reports, with the videotaped evidence; and, the proposed settlement that had been negotiated was still substantial enough to make the risks and economics of a trial unattractive.

Privacy Concerns

Insurers are allowed to conduct surveillance even though most people (and perhaps even the insurers themselves) would agree that surveillance – because of its voyeuristic quality – invades personal privacy, at least to some extent. While from a public policy standpoint, privacy rights are important to recognize, promote and preserve, several things happen when claims and lawsuits arise. When a disability claim is made, the individual is usually in a private contractual relationship with an insurer, or is a beneficiary under such contract in the case of a group policy. The claimant has placed his or her health and ability to work in issue. His or her medical history has now become relevant to the insurer. While clinical records, medical reports and employment documentation are important sources of information that insurers, to varying degrees, use to assess whether claimants satisfy the particular disability criteria under the contract, insurers seem to have a natural skepticism about whether this information tells the whole truth about the claimant's abilities or disabilities, or is the product of manipulation, exaggeration, deception or fraud. Surveillance is how insurers take a clandestine peek into claimants' lives to compare what is observed with the information it has already received (or will be receiving) regarding the claimant. Surveillance is usually carried out while the claimant's activities are taking place out in plain view – such as in a park, roadway, supermarket, mall, job-site, or other public place, or even in front of a window open to public view. The "invasion of privacy" sentiment that is expressed by claimants who know they're being investigated, or who learn that they have been, is probably more a reaction to their being "surreptitiously observed" than to any misconception that they have a right of "privacy" in unquestionably public places. (The courts have long held in criminal cases – usually involving alleged illegal searches and seizures – that there is no right to privacy, strictly-speaking, in public places, because there can be no "reasonable expectation of privacy" in those locales.)

Perception Is Reality

Since surveillance cannot be prevented, it should at least be anticipated by claimants. Claims managers may approve expenditures for surveillance where "objective evidence" of disability (whatever insurers mean by that) may be limited or lacking, even though the medical reports may arguably support ongoing disability. This has typically been the attitude in claims involving chronic pain, chronic fatigue, and fibromyalgia, although it is certainly not confined to such claims.

My advice to disability claimants and clients is simple: if you are able to push, lift and throw shovels-full of snow continuously for 30 minutes, regardless of your motivation for doing so, you may not be as physically disabled as you believe or claim you are. If you are in fact disabled, and the compromising activity you're "caught" engaging in is truly an isolated incident (making you guilty of little more than perhaps bad timing), the "able-bodied" perception that you create in those who may be observing you – whether neighbours or investigators – unfortunately becomes a "reality" that is difficult to turn around. Be ready to have a very plausible explanation.

Since insurers will not hesitate to use investigations to their advantage, regardless of what the actual state of disability may be, claimants should be astute to situations where they may find their actions manipulated, taken out of context, or blown out of proportion by zealous adjusters or their counsel.

Avoiding The Pitfalls

Long-term disability claimants often find themselves in settings where they are being asked for information about their activities and levels of function. This may involve something as basic as the completion of insurance forms, or more formal settings such as insurer medical examinations or examinations for discovery in legal proceedings.

Regardless of the setting, the best policy is to provide information that is as accurate, honest, to-the-point, and complete as possible. It is not unusual for an insurer, in anticipation of an upcoming examination, to seek to obtain activity-related information from investigations and surveillance beforehand, with a view toward *comparing* such information with that which will be obtained from the claimant during the examination. During questioning, the insurer's representative may leave clues that investigations have taken place: "Have you done any gardening since April last?"; "Have you hand-washed your car in the past 3 months?"; "Have you personally carried out the trash since you filed your claim for disability?"; "Have you toted any grocery bags in the two months since your discharge from hospital?"; "Have you visited your place of business over the past 6 months?" A simple "no" in response to any of these or similar questions is perfectly fine, as long as you're absolutely certain that it is true. We do many things over time, and few of us could actually recall everything we've done, particularly routine things that are not terribly significant in and of themselves. You may have honestly forgotten that a few months ago you carried two or three small bags of trash to the curb, or planted a few Petunias in your front garden. The insurer, however, may not have forgotten, especially if it photographed or videotaped you doing the very activity you so confidently denied doing. Your simple "no" response may now take on a meaning for your claim far beyond what you might expect. In the eyes of the insurer, and possibly the court, you are now a liar, and this will have a direct bearing on your credibility and how your claim is assessed. It also spills over into other areas. The insurer's position will be: If she's untruthful about something as relatively innocuous as planting a few Petunias, what might she be trying to conceal about something much more important. Unless you have perfect recollection, or are entirely certain about details of your past activities, it may be more appropriate to give qualified responses: "I don't believe I did, *but I can't be certain*" or "I *may have*, but I don't recall *specifically*"; or "I don't *think* I have, but it is *possible*". Should it turn out that investigations capture your involvement in the activity, it would be difficult for the insurer to make a convincing argument that your qualified response was untruthful.

Conclusion

Each year the insurance industry spends considerable amounts on claims investigations and surveillance. It does this not because of any industry-wide belief that all or most claims are fraudulent. Indeed, most veterans of the business would probably agree that insurance fraud – although a problem – represents a relatively small incidence as a percentage of overall claims.

In the LTD setting, while insurers may be looking for claimants who are deceitful – e.g. working when they claim they're not, receiving undisclosed disability benefits or payments from other sources, etc. – most investigations would seem to be directed more toward determining the extent of disability by matching the observed activities or level of activity with the job-related functions which the individual claims he or she cannot perform. The problem with that, of course, is in certain situations it may be unfair for the insurer to extrapolate from the investigator's observations: doing stretching exercises in the park, driving to the local convenience store, strolling in a mall, or swimming laps, may all create the appearance of health and wellness, yet may be completely unrepresentative of the physical, cognitive and emotional demands of a fast-paced, high-pressure workplace. Having said that, be mindful that the more rigorous, enduring or "work-like" the activity that is observed, the more unrelenting the insurer is likely to be in maintaining its denial.

The obvious way to avoid the pitfalls of investigations and surveillance, is to carry on in a manner that is consistent with your true level of ability and, if questioned, to provide appropriate and truthful responses about what those abilities are and aren't. Openly admitting to what you can do (or can do only with limitation, restriction or pain) may significantly bolster your credibility when describing what you cannot do.

If the activities observed by an investigator happen to fall within the boundaries of any limitations set by your physician, there shouldn't be much problem either. If your physician or therapist encourages exercise, swimming, walking, gardening, or other activities, surveillance that "exposes" this behavior won't be of much value to the insurer – at least from the standpoint of credibility – unless you subsequently deny the activity when questioned about it.

When it comes to investigations and surveillance, know what you're up against. Remember…there is no law that says you can't be as astute as your insurer, or that you're not allowed to play by the same rules.

Insurance Company Stalling Backfires

Lawrence E. Pierce, Pierce Law Group

The British Columbia Court of Appeal recently decided in Balzer v. Sun Life, that letters sent to Ms. Balzer about her disability insurance claim would not prevent her from suing more than one year after Sun Life refused to pay because Sun Life never said clearly that they would not pay, and that she had only one year to sue.

Ms. Balzer became disabled in 1992, and was paid during the "own occupation" period. That lasted until 1994 when Sun refused to pay, and over the next few years several letters were sent to her by Sun Life saying they would review their decision if further medical information was provided.

Further medical was provided, but Sun Life continued writing the letters asking for more information, each time promising to review the decision if the information was provided.

Finally in 2000, Ms. Balzer hired Pierce Law Group to sue Sun Life. After winning on Sun Life's motion to strike out the law suit because it was started more than one year after the denial, Pierce Law Group won again in the Court of Appeal.
The Court said at paragraph 10 :

" However, in its correspondence with Ms. Balzer, Sun Life at no time suggested time was running against her claim to 'any occupation' coverage, that she was required to file a new proof of claim for that coverage, or that her time for making that claim had expired…"

The rule in B.C. had been that, on a disability insurance case, the time to sue was over one year after the claim was denied.
The B.C. Court of Appeal said at paragraph 45:

Any ambiguity in the communication of a refusal of benefits, as to whether it is a clear and unequivocal denial, should be resolved in favour of the insured (Ms. Balzer in this case .) To avoid any doubt, the preferred course for an insurer (i.e. Sun Life) intending to deny coverage should be to include an alert in the letter drawing the insured's attention to the one year limitation in s. 22(1) (of the B.C. Insurance Act) and informing the insured that the insurer will rely on the denial as starting the running of time.

The Court went on to say there should be no limit on the arrears Ms. Balzer can collect… all the way back to 1994 plus interest!

Any one who was denied by a disability insurer in the last 15 years, and who missed the limitation period, or never tried to sue, should consult a lawyer to see if it is still possible to sue, and get all the back payments, and the future payments.
Pierce Law Group is a Vancouver law firm specializing in disability insurance law **www.bcdisabilitylaw.com**
Full text of Balzer v. Sun Life: **2003 BCCA 306 Balzer v. Sun Life Assurance Company of Canada**

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Please contact the **National ME/FM Action Network** if you need the name of a lawyer or doctor in your area who is on our National Lawyers' or Doctors' Roster.

ME/CFS and FM in Young People – School Issues

Margaret Parlor, Advisor on Youth Issues

"I didn't know kids get it." This is a reaction I have heard numerous times. Unfortunately young people do get ME/CFS and fibromyalgia. And they get it in sizable numbers.

The leading study on the prevalence of ME/CFS was done by Dr. Dowsett and Jane Colby in the United Kingdom. They asked schools about student absences of two months or more during the previous two years. ME/CFS was the reason given in 51% of the cases, well ahead of cancer, depression, school phobia, injury, or any other reason for absence that might have been expected. The study found a rate for ME/CFS of 70 per 100k students. There is reason to suspect the study understates the real rate. This is not a reflection on the researchers; they were dependent on doctors to identify and report the condition, on schools to complete the questionnaire, and on students to remain in the school system.

Here in Ontario, the education system seems somewhat unaware of ME/CFS and FM and the impact they can have on students. Thus, for instance, the Ministry of Education did not think to invite the provincial ME or FM organization to participate in its comprehensive review of policies and procedures for students with special needs. At a local level, at least one major school board did not think to list home instruction as a possible placement for special needs students.

While there is a general lack of awareness, there is also a general openness to learn. With the recent publication of our Network's **Teach-ME Sourcebook: A Sourcebook for Teachers of Children with ME/CFS and/or FM**, we have a tool to inform educators of the issues. The **Myalgic Encephalomyelitis Association of Ontario** has raised money to purchase our Sourcebook and has distributed them to school boards in Toronto and Guelph, and is targeting Peterborough.

The **Fibromyalgia Association Niagara** used their conference earnings to purchase our Sourcebooks and has distributed a copy to every school in the Niagara District School Board. The Niagara Catholic Board (which was a little late IN responding) is next on their list. At the same time, I have been piloting presentations in Ottawa - the first to school attendance officers on recognizing and understanding ME/FM among students and the second a brief introduction for senior administrators on ME/FM student issues.

The **Ontario Myalgic Encephalomyelitis Association of Ontario**, with the endorsement of the **Ontario Fibromyalgia Society** and the **National ME/FM Action Network**, contacted the Minister of Education to draw her attention to the particular needs of ME/CFS and FM students. In late May, a meeting was held with Ministry officials. Many good ideas on raising awareness were discussed, but somewhat disappointingly the Ministry did not appear to want a proactive role. The groups are looking at the various ideas, and are considering a follow-up with the Minister

The **National ME/FM Action Network** recognizes the importance of education for young people with these conditions. We would like to hear your feedback and opinions on these issues.

Doctors in "GOOD STANDING" – What Does it Really Mean

Mary Ellen, Manager of Special Projects

Our National Registry of information about patients around the country who have been requested to attend an independent medical examination (IME) or functional abilities evaluation (FAE) at the request of private insurance companies, Canada Pension Plan and Workers Safety and Insurance Boards, contains a wealth of information. The information is alerting us to many inherent problems within this biased system.

For example, thanks to copies of letters of complaint to regulatory bodies, and copies of decisions about disciplinary actions taken against these doctors, the **National ME/FM Action Network** is aware that many patients are still being sent for IMEs to doctors who have received disciplinary action by their regulatory bodies. The same Colleges that disciplined these doctors are telling patients that these doctors are members in "good standing".

Armed with this information, on May 20, 2003, the **National ME/FM Action Network** sent a letter to one of the provincial colleges of Physicians and Surgeons and asked:

"Doctors listed on the Financial Services Designated Assessment Centres' Roster are purported to be 'members in good standing' with the College of Physicians and Surgeons of Ontario. So too are doctors listed on the Workers Safety and Insurance Board's Roster. On precisely what criteria is the 'good' in good standing bestowed and on what grounds would the 'good' in good standing be revoked? We look forward to a reply to this question at your earliest convenience."

We are still awaiting their reply.

Please, if you have been requested to attend an IME by a private insurance company, CPP, or WSIB, fill out our confidential Registry Submission Form so that we can continue to track those IME doctors whom patients feel are performing inaccurate and biased reports and send us a copy of your letter of complaint to the appropriate regulatory college. Place a cc. National ME/FM Action Network at the bottom of your letter so the College is aware that our organization is tracking their decision. We would be pleased to help with letter writing for those needing help because of cognitive problems or fatigue.

All across the country, we are making gains in raising awareness about this serious problem because of the efforts of patients willing to complain about this injustice.

To receive a copy or copies of the simple, confidential, 7 question Registry Submission Form, please Contact:
Mary Ellen, Manager of Special Projects, Phone or fax: (905) 831-4744
Mail: P.O. Box 66172, Town Center Postal Outlet, 1355 Kingston Rd., Pickering, ON., L1V 6P7 - Email: **marye@pathcom.com**
Or download the Form from our website at www.mefmaction.net/medexam.html

BOOKS / REPORTS ETC. ***Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols (Journal of Chronic Fatigue Syndrome, Volume 11, Number 1, 2003)*** is available for **U.S. $14.95** per copy plus $5.00 Shipping **and** Handling. To order, contact **The Haworth Press, Inc.,** 10 Alice Street, Binghamton, NY 13904-1580 USA**.** Telephone in US/Canada: **(800) 429-6784,** Telephone outside **US/Canada: (607) 722-5857, fax: (607) 771-0012,** email:**orders@haworthpressinc.com** **Online: http://www.haworthpressinc.com/store/product.asp?sku=4958**

INTER-GROUP/CONTACT COMMUNICATION:

THE MYALGIC ENCEPHALOMYELTIS ASSOCIATION OF ONTARIO IS HOSTING A ME/CFS MEDICAL INFORMATION SESSION:
DATE: **SATURDAY, JUNE 21, 2003** - TIME: **1:00 PM - 4:00 PM**
LOCATION: **CITY HALL, 100 QUEEN STREET WEST, TORONTO - IN THE COUNCIL CHAMBER**
Take East Elevators to '3C ' (set of 6 elevators)
TIME: REGISTRATION BEGINS AT 12:00 NOON
SPEAKERS: **DR. ALISON BESTED F.R.C.P.(C)** - Dr.Bested has a wealth of knowledge of ME/CFS
DR. PETER POWLES, Sleep Disorder Consultant, Chief of Medicine, St.Joseph's Health Centre, Toronto , Professor, Faculty of Medicine, University of Toronto
BREAK - Juices will be available in the Members Lounge
DR.ALAN C. LOGAN, DOCTOR OF NATUROPATHIC MEDICINE - Dr. Logan has co-authored M.E./CFS research papers with Dr. Bested and is an Alumnus of Harvard Medicine School's Clinical Training in Mind-Body Medicine
SHORT QUESTION AND ANSWER PERIOD
FREE ADMISSION - UNDERGROUND PARKING $6.00
CLOSEST SUBWAY STATIONS: Yonge and Queen or University and Queen
For more information contact: **The Myalgic Encephalomyelitis Association of Ontario**, P.O. Box 84522, 2336 Bloor Street West
416-222-8820 or 1-877-632-6682 - Web: **www.meao-cfs.on.ca**

OUR WORLD:
ME/CFS and FM MEDICAL TESTS: The Houdini Syndrome: 'Now you see it. Now you don't'.
DEFINITION OF ME/CFS and FM: In motion on empty.

RESOURCE BOOKS:

QUEST COLLECTION" BOOK - FIVE YEARS: By popular request, the **National ME/FM Action Network** has published an easy to read book consisting of a **collection** of important articles which have appeared in our **'QUEST'** newsletters over the years. For easy reference, these articles have been grouped into sections, according to their focus i.e. medical, legal etc. We have kept the **cost** of the book to a minimum of **$20.00** each which includes shipping and printing. Please make **your cheque payable to the National ME/FM Action Network** and let us know how many copies you would like.

TEACH-ME - Sourcebook for Teachers. We are proud to announce that the hard-copy of **our Sourcebook for Teachers**, an educational resource book full of information and teaching strategies for teachers and parents of children and youth who have ME/CFS and/or FM, is now available. Price **$22.00** (includes S & H) – Discount on bulk orders. Cheques payable to the **National ME/FM Action Network**. Please also see our youth and parents' pages on our website at: **www.mefmaction.net**

LEGAL/RESEARCH PACKAGE - **Medical** and **Legal** Information on ME/CFS and/or FM, a resource for lawyers, advocates, doctors and patients. Please make **cheque payable to Marj van de Sande** in the amount of **$25.00** (our Director of Education) to cover photocopying, postage charges etc., **151 Arbour Ridge Circle NW, Calgary, AB T3G 3V9 -**
Tel/Fax: (403) 547-8799. E-mail: mvandes@telus.net

MEMBERSHIP: **$25.00 per year which includes bi-monthly newsletters** – Payment can be made by **CHEQUE, VISA or MASTERCARD** - **NATIONAL ME/FM ACTION NETWORK, 3836 Carling Ave., Nepean, ON K2K 2Y6 Canada –**
Tel/Fax: (613) 829-6667 –
E-mail: ag922@ncf.ca - Web: http://www.mefmaction.net

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